Deep Pockets or Blueprint for Change: Traumatic Brain Injury (TBI) Proactive Strategy

D. William Wood, MPH, PhD*; Sandra Pohl, MSW, MPH**;
Sharon Lawler MD***; Gary Okamoto MD****

The Pacific Conference scheduled for October 1-3, 1998, is a critical event in the development of an integrated community-based plan for a comprehensive continuum of services to address the "silent epidemic," Traumatic Brain Injured (TBI). This paper provides insights of the complex nature and the special problems faced by the TBI survivors; their families, natural supports and caregivers, as well as the health, social and educational care providers in Hawaii. Process for the development of the community plan is presented.

Unless we are willing and able to remove all risks from our day to day lives, Traumatic Brain Injury (TBI) will continue to occur. Nationally, every 17 seconds a person sustains a TBI. It has become the number one killer and cause of disability in the United States.[1] Approximately 2 million Americans experience moderate to severe TBI every year. About half of these cases result in short-term disability, fifty-two thousand people die, and seventy thousand to ninety thousand endure lifelong multiple loss of functions. An additional two thousand will exist in a persistent vegetative state.[2]

The number of individuals with brain impairments is increasing significantly. As recently as the early 1980's nine out of ten died, but in the 1990's nine out of ten survive due to new medical technology, aggressive patient management, and quick effective emergency response at the point of injury and in the trauma center. Long known as the "silent epidemic," everyone is at-risk—any age, any time, any place. The major causes of TBI are motor vehicle accidents (50%), sports accidents (10%), falls (21%) and firearms (12%) and other reasons (7%). Alcohol is an associated if not a causal factor of TBI: 50% of persons were intoxicated at the time of injury.[3]

The Cost of Brain Injury

Brain injury is a life-long disability, with no cure. It also does not just go away. It is considered the most expensive disability with the life-time estimated cost for one severe injury at $4 to $7 million. This is about 5 times more than the life-time costs of treating one severe spinal cord injury. In addition, annually there is an estimated 10,000 spinal cord injuries compared to the 2 million TBI.[3]

Families and survivors of TBI quickly use up their limited health insurance coverage and soon after exhaust their personal resources. Impoverished by their large outstanding bills from the health care facilities, they often default in payments leaving health care providers unpaid. Disabled and impoverished, survivors apply for Medicaid or Medicare benefits to pay for their health care needs. If ineligible for public assistance however, they may go without medical attention until their secondary disabilities develop into more extensive preventable medical-social complications.

The Brain Injury Association of Kentucky identifies another factor to the crisis which will be faced by every state and the nation in the near future. The caregivers are older and are more frail and dying, their abilities to continue providing home care has diminished. The crux of the problem is the demand for more resources to meet the long term care needs of the aging brain impaired population as well as their aging caregivers.[3]

The health care system has experienced major unforeseen consequences impacting the existing costly infectious disease trauma-based system. This means that relying on the existing system alone is not feasible because the survivors and their families are already financially weakened. They will be unable to sustain the provision of needed resources in the long term. The same is likely true for other disability groups.

Federal Law Encourages Community Involvement

The Traumatic Brain Injury Act, P.L. 104-166, 104th Congress (1996) established a national program to promote basic and applied

*Interim Dean
University of Hawaii School of Public Health
1960 East West Road
Honolulu, Hawaii 96822
(808) 956-8066 Fax (808) 956-4585

**Brain Injury Association of Hawaii
Health Education Consultant

***Hawaii Medical Association
Community Research Bureau
Internist, Private Practice

****Member of the Traumatic Brain Injury
State Advisory Board
Department of Health
Physiatrist, Private Practice

For more information contact:
Sandra Pohl, MSW, MPH.
Consultant
3507 Nuuanu Pali Drive
Honolulu, HI 96817

research with respect to prevention and to minimize the extent and the severity of impairments caused by TBI. The program also offered grants to states for establishing demonstration projects in the form of matching of two dollars for every dollar appropriated by the state. The TBI projects will foster person and family centered care which requires: involvement of survivors and their families in all phases of the TBI continuum of care; clear and continuous communication between family members and the care teams; attention to the psychosocial needs of survivors and family members; and cultural competence of the providers.[4]

What is TBI?

The federal statute (PL 104-166), defines TBI as an acquired injury to the brain, a broad category that includes other neurological disorders. However, it does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning. TBI is different from other brain injuries as the damage happens during what may well have been normal development; it happens suddenly, bringing significant changes immediately; damage is usually diffuse, widespread, and not confined to one area of the brain.[4]

TBI can be caused by an external mechanical force or motion to the head region. An open brain injury caused by a foreign object penetrating the skull and lodging in the brain (an example is a gunshot wound.) A closed Brain Injury occurs when the head accelerates and then rapidly decelerates by violent smashing, shaking, stretching, and twisting of brain tissue; the nerve endings connecting the skull to the brain are often torn or may become completely separated.[5] Examples of closed head injuries are whiplash or shaken baby syndrome.

Simple Bump on the Head or is it TBI?

Due to the lack of emergency, most mild and moderate TBI injuries are not noticed or diagnosed, and often it is assumed everything will be okay — life as usual when the pain goes away. Survivors may appear to be fine with no obvious physical symptoms, but the cognitive, social, emotional, behavioral losses of function and the changes in personality are very real.[3] The brain injuries that require medical attention are often discharged from the emergency room with few instructions and minimal follow-up. This only indicates that the patient has no gross symptoms or reactions and is medically stabilized at the time of the examination. Survivors and their support system sense something is not quite right but do not relate the changes with the brain injury. They seek acute health care and report their symptoms without mentioning the injury. Uninformed or unaware of brain injury, the health care providers and professionals unintentionally may make diagnosis and referrals to inappropriate treatment. This only adds to the cost of care as well as cause additional confusion and stress to the family and support systems.

Brain Impairments are Unique with Every Person

Unlike other disabilities, there is no diagnostic criteria to rule out brain impairments. Each brain injury survivor requires an individual assessment and evaluation because of the very subtle multiple deficits in one or more areas in different degrees and the extent of the injury. The symptoms include: hypersensitivity to stimulation, metabolic and neurological disorders, sexual dysfunction, sleep disturbance, fatigue, lethargy, cognitive problems of short and long term memory deficits, speech/language impairments, learning disabilities, difficulty with perceptions, concentrating, reading and writing, impaired executive functions i.e. plan, make judgments and think quickly as well as understand complex issues. There are also the psychosocial-behavioral-emotional consequences such as irritability, aggression, violent reactions, restlessness and anxiety, lack of spontaneity, childishness, apathy and depression, mood swings, denial, self-centeredness, lack of ambition, indecision, lowered self-esteem, sexual disinhibition, difficulty with emotional control, unable to develop personal relationships, excessive emotions (i.e. laughing, swearing, or crying), etc.[5] These symptoms are similar to other primary diagnosis (mental illness, behavior disorders, chronic fatigue syndrome, etc.) Often these diagnosis are used without any reference to the organic dysfunction due to tissue damage.

Pediatric TBI is Different from Adult TBI

The National Pediatric Trauma Registry identified brain injury as the most frequent diagnosis reported and the leading cause of death and disability in children and adolescents: one million children are taken into emergency rooms each year with brain injuries.

For children, the neurological consequences of an injury to their undeveloped brain most often have negative results on future education, vocation and the quality of life as they mature, develop and live their normal life spans. Brain impaired students have unique considerations for community reintegration. The brain impaired have tendencies to "absorb" the behaviors exhibited by those around them and they very often cannot generalize what they have learned in one situation to another, etc.[3] In addition, for children and young adults some dysfunctions develop when physical maturity requires functions from the injured parts of the brain.

The majority of students return to school with different educational and emotional needs from their pre-injury development. Although students with TBI may seem to function much like children born with other handicapping conditions, but the unexpected disability resulting from trauma is very different. TBI Children can often remember how they were and what they could do before the injury. This can result in significant emotional, psychosocial and relationship problems not usually present in children born with disabilities. Further the trauma impacts family, friends and professionals who remember the pre-injured child. Everyone grieves the loss of functions and potential often without hope of recovery. Confused and frustrated, the caregivers and natural support system have difficulty in shifting and adjusting to the changes as a result of the injury and the increase demands on care giving.[7]

Educational Implications

Unidentified and not evaluated, students with TBI are too often inappropriately classified as having learning disabilities, emotional disturbances, or mental retardation, mental illness, etc. As a result, the appropriate medical, educational and related services to address the brain injury may not be prescribed.[8]

TBI is a separate disability within special education. The schools are held responsible to provide children and youth with access to and funding for neuropsychological, speech and language, educational, and other evaluations necessary to provide the information needed

for the development of an appropriate individualized educational program (IEP). According to Debosey, careful planning for school reentry (include linkages between the trauma center/rehabilitation hospital and the special education team at the school) is extremely important in meeting the needs of the student's successful community reintegration and regaining functions to be on track with their developmental and educational tasks as well as catch up with their peers.[9]

Need for Medical Self-Sufficiency

Hawaii is unique in that, unlike other states it is located in the middle of the Pacific Ocean, 2,300 miles away from the continental United States and is comprised of island counties. The distance between the islands and from the mainland U.S. isolates residents from easily accessing and exchanging services and resources of any neighboring communities.

The augmenting of the state's 1.3 million residents by over six (6) million tourists annually also creates unique service delivery problems. The year round mild climate increases the risk of preventable TBI from outdoor and recreational activities of both residents and tourists. Because little opportunity exists to learn of the unique personal behaviors, baseline brain activity and because tourists engage in higher risk activities on vacation then in their normal lifestyles, the complexity of their trauma cases is intensified. Finally, the cultural differences within the multi-ethnic communities and their associated lifestyles, the social services and health care models from elsewhere do not seem appropriate for Hawaii. Thus, the development of sustainable solutions relying on the islands' self sufficiency is essential.

Like most other States, the TBI community's (survivors, families and caregivers) needs are only now being addressed through the Federal initiatives and the availability of matching grant funds.

Gross Underestimation of TBI

The Healthy People Hawaii 2000 Objectives, the National Health Promotion and Disease Prevention Objectives reported the incidence of moderate and severe brain injuries is similar to other states.[10] A 1997 Hawaii Health Information Corporation report identified approximately 1,200 TBI discharges from Hawaii's hospitals annually of which 2/3 were residents and 1/3 tourists. These patients are distributed across twenty of the State's 22 health care facilities with acute care capacity. Fourteen percent are children ages 0-14 years; 43% are ages 15-44. Over the period 1993 through the first quarter of 1996, the average cost per discharge was $22,048. The total hospital cost for the emergency room or initial acute hospital admission for the TBI discharges are estimated at $26.6 million per year.[11] The numbers do not account for the admissions with other primary diagnosis, the mild to moderate brain injuries that did not require medical attention and those already living in the community with TBI related disabilities. The required funds and resources needed to treat Hawaii's TBI survivors under the present system cannot be seen to meet the known and unknown need.

TBI Advocacy

During the 1997 Legislative session, the Hawaii Medical Association (HMA), the Brain Injury Association of Hawaii formerly

known as the Pacific Brain Injury Association (PBIA), the University of Hawaii School of Public Health (UHSPH), the Hawaii Nurses' Association (HNA) and the many TBI advocates were able to provide convincing data to the Legislatures. The growing political-will to develop local solutions is indicated by the unanimous votes in both houses of the State Legislature and the Governor signing Act 333 relating to TBI on July 2, 1997. In addition, the 1998 Hawaii legislature appropriated state funds to match federal or other private foundation funds.

Community Challenge—Opportunities for Collaboration

The purpose of the community planning process is to identify needs, resources and local solutions through citizen participation. The success of the planning process will reflect genuineness of the communication, cooperation, coordination and collaboration between the public and the private sectors.

Reality of Private-Public Partnerships

These are difficult financial times in which to create a continuum of services given the State's fiscal constraints, the outcry for downsizing government and reduction of the state's income projections. The cost of acute care and long term care, managed care cost containment policies also exacerbate the problems and increase the public burden (cost). With the shortage of resources and the growing need, can Hawaii continue providing services without a plan? The choices are to 1) continue as is, 2) break the bank with band aid approaches, or 3) develop a proactive strategy for an integrated comprehensive continuum of care for all individuals with brain impairments and support services for their families and caregivers statewide.

HMA Committee for Neuropsychology

Committee for Neuropsychology — Hawaii Medical Association Community Research Bureau was formed in 1996 to address the gaps in services. The members of this public-private coalition include: Hawaii Medical Association, Brain Injury Association of Hawaii formerly the Pacific Brain Injury Association, Department of Health Neuropsychology Services at the State Hospital, The Department of Education Special Education Services, University of Hawaii School of Public Health and the Department of Psychology, and families/caregivers. The committee is establishing the Hawaii Neuropsychological Community Research Bureau, as an education, research and development infrastructure for cost-effective neuropsychology programs. In addition, they have also collaborated with other agencies to sponsor educational forums for the general public, the TBI community, health care and education professionals.

The Committee on Neuropsychology has the freedom and flexibility to expand or contract as the need grows or shrinks. The vision is to develop diverse local solutions that are built on real private-public partnerships to do "whatever it takes" to meet the needs of its partners to provide family and survivor centered care.

What's the Problem

There is a need to have a more accurate count of the individuals with brain impairments who need special services to implement the size of programs and type of services. The comprehensive assessment survey developed by Federal Health Resources and Services Administration, Maternal Child Health Division (HRSA/MCH) will be modified to account for the unique ethnic demographic distribution. The assessment will be distributed to the following groups as defined by HRSA/MCH: 1) TBI survivors, 2) family members, 3) service providers, 4) private and public agency administrators. This assessment process will supplement other data collection efforts.

"Barefoot Epidemiology"

The Community Epidemiology Work Group (CEWG)[13] process will provide rough estimates of incidence and prevalence rates. But more importantly, the CEWG will create opportunities for the stakeholders to discuss the problem, and participate in a process of consensus building. The CEWG is an effort that has been well defined in the field of substance abuse.[13] Known as "barefoot epidemiology," it relies on the knowledge and information from those "who ought to know" as a primary source of information.

The primary purpose of the CEWG is to build a foundation for the interaction of providers and researchers in a non-threatening environment with the intent of identifying what we know and what we need to know. Health care professionals and their agencies share information that was previously viewed as proprietary. This coalition is vital in reinforcing the need for "standardized" methods of case determination, a minimum data set for individuals with TBI, and an overall improvement of data collection. No attempt is made to develop precise prevalence rates since the data provided simply

do not lend themselves to that precision. Instead, prevalence ranges and estimates of what might be are made. This process brings the stake holders together to build the infrastructure for the TBI surveillance system in the state.

Second, the information collected provides an invaluable tool for professionals in the community to plan cost effective services for the needs of individuals with TBI as well as provide all organizations within the community a resource for referring TBI cases to providers of care.

Third, Hawaii has a mix of ethnic communities who may have differing prevalence rates of TBI as well as differences in socioeconomic status, age, and gender. To provide Hawaii's residents with more effective health promotion and disease prevention programs, it is important to understand the magnitude of the problem within the ethnic community and to determine what factors shape health behaviors.

The CEWG data will be paralleled with an analysis of the consolidated inpatient data as well as available outpatient data. Finally, data from the state emergency medical system will be factored in to complete the basic data for the assessment of services to identify the profile of unmet needs and useful information related to prevalence rate determination. It will also provide information to: 1) develop a monograph on TBI in Hawaii; 2) encourage researchers to identify research projects for future grant applications and 3) implement cost effective demonstration projects with strong evaluation components to self correct the programs.

Understanding is Critical to Informed Choices

The role of all education in the development of the comprehensive TBI program cannot be emphasized enough. In fact, this may be the one area where substantial change can be instigated in a short period of time. Educational improvements may be more human related technology and less reliance on expensive high technology medical care.

Teaching survivors and caregivers leadership, advocacy and coping skills will encourage cooperation and smoother dynamics. The survivors and their caregivers are able to ask the right questions, participate as a member of the trans-disciplinary care team providing the needed care and involved in making informed choices. This skills development and information dissemination strategy is a simple cost-effective means of improving the system.

TBI education may also alter the environment in which more expensive and extensive inter-related program components will later evolve such that the medical community, allied health professionals and the community at large may understand and be willing to facilitate and advocate for positive change.

Start Somewhere Sometime

The start of the planning process begins on October 1-3, 1998 with the Pacific Conference on Brain Injury focusing on prevention of Family Violence Induced Brain Injuries and the Continuum of Care. The first progress report, tentatively scheduled for October 1999, will make recommendations for no cost public policy changes and other proposals to increase access for services without sacrificing the quality of health care.

Impact of Community Proactive Strategy

In the end, a community and its government are judged by how they address the civic responsibility for the health and well-being of all citizens. The community involvement gives citizens the power to direct the public sector in how best to utilize resources for a more responsive government.The private sector has the flexibility to develop new small businesses and new jobs to fill the needs as identified during the process.

The implementation of an action plan may save considerable sums of money. The current practice of discharging the brain injured by health insurance authorization criteria of sicker and quicker, only to have them return because of complications. With effective rehabilitation, survivors may regain functions quicker and is ready for earlier discharge to lower costs community based services to transitioning back to independent living.

This practice of discharging severe to moderate brain impaired survivors from the acute care system (acute rehabilitation costs of $20,000 to $30,000 per month), and transferring to less expensive community based services, (residential rehabilitation costs of $7,000 to $15,000 per month) will save money in the long term. In addition the survivors live in the least restrictive environment moving through the community based continuum of care to achieve their highest potential and an increased quality of life.

"Hawaii the Health Care Center of the Pacific."

Nationally, the TBI industry is the fastest growing and most profitable niche medical sub-specialty. This is one way of diversifying our economic base by providing specialized appropriate and effective brain impaired services provided by the private sector.The State of Hawaii has the infrastructure and professional leadership to become the pioneers in brain injury treatment, education, training and research development. "Hawaii the health care center of the Pacific" is possible. The support to develop community-based partnerships that build "Centers of Excellence," requires support from all sectors of the community. The added benefit is the money will stay in the community multiplying by a factor of 2.1 and in turn generate more state income.

References

1. Brain Injury Association, Inc. Alexandria, Virginia. Fact Sheet Traumatic Brain Injury, 1997.
2. Session Laws of Hawaii, Nineteenth State Legislature, Regular Session of 1997, Act 333 page 971.
3. Brain Injury Association, Kentucky.Brain Injury Creates a Unique Challenge. Residential Concerns Task Force Report, 1997.
4. Department of Health and Human Services, U.S. Public Health Service. Application Guidance for Traumatic Brain Injury (TBI) Demonstration Grants Program CODA #93.TBI, March 1997.
5. Smith, L.M. and Godfrey H.P.D. Family Support Programs and Rehabilitation. A Cognitive-Behavioral Approach to Traumatic Brain Injury. New York, Plenum Press, 1995.
6. Snow J.H. and Hopper S.R. Pediatric Traumatic Brain Injury. Thousand Oaks, California, Sage Publications, 1994
7. National Information Center for Children and Youth with Disabilities (NICHES). Traumatic Brain Injury Fact Sheet Number 4 (FSS4), Washington, D.C., 1997.
8. Savage, R.C. Children with Traumatic Brain Injuries. Randolph, MA: May Institute, Inc.
9. DeBoskey, D.S. (Ed.). (1996). Coming home: A discharge manual for families of persons with a brain injury. Houston, Texas: HI Publishers.
10. U.S. Department of Health and Human Services, Public Health Service. Healthy People 2000 National Health Promotion and Disease Prevention Objectives.Washington, D.C. DHHS Publication No. (PUS) 91-50213
11. Forbes, S. Special Report on Brain Injury Discharges. Honolulu, HI: Hawaii Health Information Corp, 9-17-97.
12. Health Resources and Services Administration/Maternal and Child Health Division. Traumatic Brain Injury Needs/Resource Assessment Tool. Silver Springs, Md. Department of Health and Human Services, U.S. Public Health Service,1997.
13. Kozel, N.J. The Role of Networks in Drug Abuse Surveillance: An Account of the History, Implementation, and Development of the Community Epidemiology Work Group Model, 1992.